

END-OF-LIFE DECISIONS

HONORING THE WISHES OF A PERSON LIVING WITH DEMENTIA

PREPARING FOR THE END OF LIFE

When a person in the late stage of dementia nears the end of life and is no longer able to make his or her own decisions, families must make choices on the person's behalf.

Ideally, the person living with dementia has put in place advance directives that specify his or her wishes. Without such directives, or if certain issues have not been addressed, families must make choices based on what they believe the person would want. All end-of-life decisions should respect the person's values and wishes while maintaining his or her comfort and dignity.

The Alzheimer's Association® can help you prepare for making end-of-life decisions, such as:

- Advocating for care that is based on the expressed wishes of the person with dementia.
- Refusing, starting, limiting or ending medical treatments.
- Facilitating care that focuses on comfort.
- Arranging for a brain autopsy.

HONORING THE PERSON'S WISHES

A person living with dementia has the legal right to limit, refuse or stop medical treatments. These wishes are usually expressed through advance directives — legal papers specifying the type of medical care a person wants to receive once they no longer have capacity to make such decisions, and who should be in charge of making those decisions. Advance directives should be made when the person living with dementia still has legal capacity — the level of judgment and decision-making ability needed to sign official documents or to make medical and financial decisions. These documents should be completed as soon as possible after a diagnosis of dementia.

If advance directives are not in place, the family must be prepared to make decisions consistent with what they believe the person would have wanted, while acting in that person's best interest. Laws vary by state, but a spouse or adult child may have the right to make the decision to stop medical treatments in the absence of an advance directive.

Note: Make sure to use the advance directives forms that are recognized in the state where care is, or will be, provided. The Alzheimer's Association can help you locate these forms and provide more information about making legal plans.

TYPES OF ADVANCE DIRECTIVES

Living will

A living will is a set of written instructions that provides specific preferences about the kind of medical treatment a person would or would not want to have. It does not designate someone to make medical decisions on the person's behalf, but rather allows the person to communicate wishes about future care.

Durable power of attorney for health care

A durable power of attorney for health care allows a person to choose a partner, spouse, family member or trusted friend to make decisions about care and treatment when he or she is no longer able.

ENSURE ADVANCE DIRECTIVES ARE FOLLOWED

1. Give copies of the forms to all those involved in decisions, including:

- Family members.
- Doctors.
- Other health care providers.

Request to have advance directives placed in the individual's medical record. If the person is transferred to a new setting, provide copies to those newly involved in caregiving.

2. Discuss advance directives.

Family members should understand, respect and abide by the person's wishes. Discuss these wishes to work out any disagreements and help prevent future conflict or crisis decision-making. Advance directives should also be discussed with doctors and other health care providers to ensure they're aware of their patient's wishes.

Residential care communities and hospitals often offer social services that can help if a conflict develops in a family. You may also consider mediation services to help reach consensus. Single people or those in a domestic partnership should designate a person to carry out their advance directives if it is not a family member.

3. Stay involved in medical decisions.

Work with the health care team to create and follow a care plan based on the advance directives. Make sure you are kept informed of any changes in your family member's condition that may prompt the need for new decisions.

UNDERSTANDING TREATMENT OPTIONS

Deciding on treatment options in the late stage of the disease can be one of the most difficult decisions that families face. Be aware of the range of medical care available when making decisions to use, withdraw, limit or refuse treatment for the person with Alzheimer's.

Arming yourself with information and discussing options with your care team can be helpful. It's also important to ask the medical team questions to make sure you understand which treatments are suggested and why they are appropriate.

AGGRESSIVE MEDICAL CARE

Individuals who have completed advance directives may have addressed the use of aggressive medical care — measures taken to keep a person alive.

Respirators

If a person living with dementia is no longer able to breathe independently, a respirator may be used. While a respirator can help keep a person alive, it may also cause the person's body to undergo unnecessary stress, creating greater discomfort.

Feeding tubes

Feeding tubes are sometimes used if a person has a hard time eating or swallowing, which is common in late-stage dementia. However, there is no evidence that tube feeding has significant benefits or extends life

Tube feeding can result in:

- Infections.
- Need for physical restraints (the person may try to pull out the tube, causing injury).

There are other ways to feed a person in the late stage of Alzheimer's, such as by careful hand feeding. For someone who can no longer swallow, an approach focusing on comfort in dying may be most appropriate.

IV hydration

IV hydration — liquid given to a person through a needle in a vein — may temporarily provide fluid when a person can no longer drink, but cannot supply the nutrition needed to stay alive. Increased hydration may also make the person uncomfortable because it can cause difficulty with breathing.

Lack of hydration is a normal part of the dying process and allows a more comfortable death over a period of days. Using IV hydration can draw out dying for weeks and physically burden the person. If artificial nutrition and hydration are used, families will eventually need to decide if or when these treatments should be stopped.

CPR

A family may have to decide whether medical professionals should try to revive a person with cardiopulmonary resuscitation (CPR). CPR is used to restore function when a person's heart and/or breathing stops. It may include mouth-to-mouth breathing or pressing on the chest to mimic heart function and cause blood to circulate.

Consider that CPR:

- May be painful and traumatic.
- May leave the person in worse condition.
- May not prolong life.
- Is not recommended when a person is in the end stage of life.

The family can ask the doctor to sign a do-not-resuscitate (DNR) order, stating that no attempts will be made to revive the person, and place it in the person's medical chart.

Palliative care

Palliative care uses a multidisciplinary approach to treat pain and improve quality of life by addressing a person's physical, mental, social and spiritual well-being. It focuses on providing relief from the symptoms and stress of a serious illness. People may be treated with palliative care at any stage of a disease or condition, whether terminal or not.

Hospice care

Hospice programs provide care to those in the last stages of terminal illness, while also offering support services to families. Instead of seeking a cure or trying to prolong life, hospice care focuses on dignity and quality of remaining life.

A hospice team includes a doctor, nurse, social worker, nurse's aide, clergy and trained volunteers. They work together to address the physical, emotional and spiritual care of the person as well as the family. Care can be provided at home, or in a hospital or residential community.

For Medicare to cover hospice care, a doctor must estimate that the person has six or fewer months to live. Hospice benefits may be extended if the person lives longer than expected. If the person has Medicaid or other insurance, it is best to check with the insurance provider about coverage.

MAKING INFORMED DECISIONS

When advance directives are not in place or do not address every issue of end-of-life care, it can be difficult for families to make decisions. Below are some tips to help you through the process.

Focus on the person's wishes

Compare any recommended treatments or actions with the person's wishes for care, or with what you believe he or she would have wanted.

For example, consider:

- Did the person want all available treatment measures or only certain ones?
- Did the person want medication to fight pain but not infection?

Stay true to the person's values and beliefs

Consider all factors that would influence the person living with dementia's decisions about treatments and definitions of quality of life and death, including:

- Cultural background.
- Spirituality.
- Religious beliefs.
- Family values.

Make sure that the person's values and beliefs are guiding your decision, rather than your own.

Weigh pros and cons of treatments

Talk with the medical care team about the impact of using or refusing specific care treatments.

For example, ask:

- Will the treatment improve the person's condition or comfort?

- If so, how long will the treatment benefit the person's condition or comfort?
- Will the treatment create physical or emotional burdens for the person?

Compare any recommended treatments with the person's wishes for end-of-life care.

Consider where care will be given

Discuss with the care team if and when moving someone to a different setting is best.

Find out if the treatment or care:

- Can be provided in familiar surroundings.
- Requires transfer to another setting.

Sometimes the temporary transfer to a hospital for a procedure is disorienting and may be harmful to the person.

Understand the difference between withholding treatment and assisted suicide

Refusal or withdrawal of treatment, including tube feeding, antibiotics or CPR, is not assisted suicide (euthanasia). Limiting treatments lets the disease take its natural course and supports the person's comfort and dignity. If aggressive medical treatment is refused or withdrawn, the care team will still provide good physical and emotional care, and ensure the person is not in pain.

QUESTIONS TO ASK THE DOCTOR

1. What is the treatment for?
2. How will it help?
3. What are the physical risks or possible discomforts?
4. What are the emotional risks or possible discomforts?
5. Does the treatment match what the person would have wanted?
6. Are we doing all we can to maintain the person's dignity?
7. Are we doing all we can to give the person the best quality of life?
8. Is he or she in pain?
9. What can be done to ease the pain?
10. When is the best time to ask for hospice care?

RESOLVING FAMILY CONFLICTS

Family members need to take part in ongoing discussions when making decisions on behalf of their relative. Some may disagree about a recommended treatment and get angry or defensive. Or, they may refuse to engage in discussions because they feel the family is "planning for death."

TIPS FOR DEALING WITH FAMILY CONFLICT

Listen to each family member with respect

Family members may have different opinions about end-of-life preferences and quality of care. Some may not fully accept that the person is approaching death. Try to avoid blaming or attacking each other, as this will only cause more hurt.

Involve a third party

A mediator, physician, nurse, social worker or spiritual leader can be asked to facilitate family meetings and help work through difficult issues.

Cope with your feelings together

The approaching death of a family member is an emotional time for everyone and may cause people to act in unusual ways. Consider seeking emotional support, particularly during the last stage of the disease.

Contact the Alzheimer's Association to find support groups that can help your family work through emotions such as stress, guilt, depression, grief and anger.

ARRANGING FOR A BRAIN AUTOPSY OR BRAIN DONATION

The person may decide to arrange for a brain autopsy or brain donation after death — both may provide scientists with a better understanding of Alzheimer's.

Brain autopsy

A brain autopsy involves a researcher or physician conducting an examination after death to look for the plaques and tangles found in brains affected by Alzheimer's. Autopsy is the definitive way to confirm a diagnosis of Alzheimer's and may provide information researchers can use to better understand the disease.

A brain autopsy may involve cost and special arrangements. Some brain donation programs provide a free autopsy report. It is usually necessary to make arrangements for a brain autopsy before the person dies.

Brain donation

Brain donation provides an important opportunity to help researchers better understand Alzheimer's and other dementias, which can pave the way for scientific breakthroughs and improved treatments. If you are interested, put plans in place as early as possible. Making arrangements early allows scientists to learn more from the brain and make the most of this precious gift. Visit [alz.org/braindonation](https://www.alz.org/braindonation) for more information.

TERMS YOU SHOULD KNOW

Advance directives

Legal documents specifying the type of medical care a person wants to receive once he or she can no longer make such decisions, and who should be in charge of making them.

Aggressive medical care

Care and treatments meant to prolong life when a person is close to death.

Cardiopulmonary resuscitation (CPR)

CPR is an intervention used to restore function when a person's heart and/or breathing stop. It may include mouth-to-mouth breathing or pressing on the chest to mimic heart function and cause blood to circulate.

Do-not-resuscitate (DNR) order

A DNR is a doctor's order that instructs medical personnel to not perform life-saving CPR or other interventions after the person's heart stops beating or breathing ceases. A DNR is based on the patient's wishes (or the wishes of his or her representative) and must be placed in the patient's chart.

Durable power of attorney for health care

This document allows a person living with dementia to choose a partner, family member or trusted friend to make decisions about care and treatment when he or she is no longer able.

Feeding tube

A tube providing artificial nutrition when a person is unable to eat. The most common type of feeding tube is inserted through an incision in the stomach.

Hospice care

A type of palliative care provided at home, a hospital or a residential care community. Hospice care is for an individual who has six months or less to live.

IV hydration

Providing liquids through a needle into a person's vein when he or she can no longer drink independently.

Legal capacity

The level of judgment and decision-making ability needed to sign official documents or to make medical and financial decisions.

Living will

Written instructions that provide specific preferences about the kind of medical treatment a person would or would not want to receive.

Palliative care

Care that focuses on relief from physical suffering and improving quality of life.

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